



The National CJD Care Fund Fact Sheet

- **What is the CJD Care Fund**

The National CJD Care Fund is provided by NHS England to support people diagnosed and living with all forms of Creutzfeldt - Jakob disease or CJD as its commonly referred to. CJD is often rapid in nature and requires urgent access to equipment and care provisions to provide quality in life. The CJD Care Fund is able to meet an identified urgent need that cannot always be met via the more traditional NHS routes.

- **Who is the Care Fund For**

The Care Fund is for any person with a confirmed diagnosis of CJD

- **Who assesses suitability for the Care Fund**

The care fund has been commissioned to the National CJD Nurses for assessment and management of awards. Patients and their family can self refer via our team. We would then assess your needs and take your application to panel. Any professionals involved can do a self assessment and send that directly to the panel.

What takes place in the Care Fund Assessment?

Each assessment will target 4 main areas

1. Your current need and how this can be best addressed.
2. Have you tried accessing via the traditional routes
3. Does point 2 cause timely delays in accessing care and provisions
4. Would there be significant harm from the fund being denied/ benefit from it being awarded

Assessments do not require in person visits, this can be done remotely through discussion with local teams and care providers who have up to date information, this includes family and friends. Your Nationally appointed Specialist CJD Nurse will be experienced in clinical assessment and needs based decision making.

Some high cost, reoccurring packages will require in person reviews but this can be arranged at a mutually convenient time. This should not delay initial implementation of award.

- **How long does this process take**

Once your appointed nurse has assessed your need she will bring this to our Care Fund virtual panel for final approval. Your application will be discussed and a decision will be made, this usually happens within 24hrs of assessments.

Once you are approved you appointed CJD Nurse will send you or your representative an award letter detailing the amount and the use. This is your copy. A similar letter will be sent to the company who is going to be providing your care or equipment to ensure they understand how the Care Fund works.

- **How much can I be awarded**



Each request is different and we review them on an individual basis. We will always try to ensure all costs are covered if there is an identified need. Any high cost packages will require in person reviews, this does not delay implementation.

Each case is considered on an individual basis, we must however be aware that the package needs to be accessible for all our patient group, anything extremely costly will need to be sent to NHS England for additional approval and in this circumstance it may exceed the approval wait time. We will always try to manage this without detriment to the individual applying.

- **How many applications to the Care Fund can I make**

You can apply for multiple applications if the need arises.

- **What happens if I am not approved**

There are some cases where your Nurse will be unable to approve an application for panel. This is rare but would be explained to you in full with reasons noted. If you feel this is unfair and require further support you can ask for a new CJD Nurse to be appointed and review your need.

If your decision is not approved at panel this will again be discussed with you giving clear reasons as to why. Your CJD Nurse should provide alternative options and work with you to achieve an outcome that benefits the applicant and meets their need.

- **What can the Care Fund be used for**

The Care Fund can be used for provisions you may need to enhance your care journey. We can assess and provide funding for mobility aides, home adaption's and equipments as well as direct care provisions while routine funding is arranged

I want to choose my own supplier for the care and equipment.

While we will always try to accommodate your wishes there are instances we would need to use our own approved suppliers, this is down to how money is spent via the NHS and ensuring public funds are being spent via reputable companies. If you have any concerns please discuss with your Nurse

- **Will I need to declare my income and or saving and will I be liable to make payments**

No, the Care Fund is not means tested in anyway. All payments and plans will be drafted between the supplier and the Care Fund team, this is something you do not need to worry about.

- **Will This effect my other funding and care**

No, this should not affect any current processes in place. The Care Fund is often used in bridging into other services or in conjunction with other services to ensure the patient group has timely and appropriate access to care and equipment that meets their changing needs.



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- **Can the fund be back date for work I have carried out already**

This is a difficult area for us to cover; currently we cannot backdate the Fund for work taken on before we had our panel approval and agreement to support. However, it is worth discussing with one of the Care Fund Nurses to see if there are other avenues of support.

For further information or discussion please contact your nationally appointed CJD Specialist Nurses.

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